

## Where Are the Parents?

By Sue Stuyvesant

Hey everyone,

For those of you who don't know me (I'm only an occasional poster) I am mom to Michelle, 9 years old, microcephalic, athetoid/spastic CP, Cortical Visual Impairment, Seizure disorder -- and CUTE! Ok, now for the reason I'm posting. To make a long story short, earlier this week a question was asked by some nitwit official as to why there weren't more parents (of special needs kids) involved in the local PTA and other issues that have come up that directly involve our kids. His question, which was passed on to me was "Where are the Parents?" I went home that night, started thinking - and boy was I pi\*\*ed -and banged this "little" essay out the next day on my lunch break. My friends thought I should share it all with you, and I apologize for the length, but I wanted you to have it all. By the way, I took copies of this to the school board meeting that night, gave it to a couple of influential people and it WILL get around.....

### **Where are the parents?**

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

### **Where are the parents?**

They are at home, diapering their 15-year-old son, or trying to lift their 100 lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

### **Where are the parents?**

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for test results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

### **Where are the parents?**

They are sleeping in shifts because their child won't sleep more than two or three hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

### **Where are the parents?**

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working two and sometimes three jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

### **Where are the parents?**

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

### **They are busy, trying to survive.**

Sue Stuyvesant  
10/15/96

---

Permission to duplicate or distribute this document is granted with the provision that the document remains intact.

<http://www.oafccd.com/lanark/poems/whereare.htm>

## Look Through the Windows of My World

By [Pat Linkhorn](#)

### An open letter to educators from parents of children with special needs.

*This "open letter" is, of course, not representative of all parents of children with disabilities, but I've tried to make it a fair sampling of the views I've heard expressed from other parents. I know I won't live to see Utopia and my children probably won't either, but the laws that are being passed today providing inclusion of children with handicaps into public schools give educators the opportunity to make this a generation of better people. And that's one step closer!*

You can't walk a mile in my shoes, but take a short journey with me and I can show you scenes from my life. You're the person responsible for my child's education - a superintendent, a principal, a teacher, a guidance counselor or a special education director. The object of this is not to make you feel sorry for me. It's to try to help you understand me and my child. If you can understand something about the places I've been, you may be able to understand where I'm coming from today.

This first window shows you a death. It's not a typical death. We didn't get flowers or have calling hours. It was a very private affair and not too many people even realized it at the time. This was the death of a dream.

You see, I always thought I'd grow up, marry and have a couple of "normal" children. When this death occurred, and it doesn't matter whether it happened when my child was first born, or as he began to develop. My whole life changed. I hadn't planned to have a child who had to use a wheelchair, or who would never be able to hear or see, or who couldn't "pass" a standard I.Q. test. I was forced to change my whole outlook on the future. It may have taken a while to go through all the stages I had to go through to get to where I am today. There was grief. A lot of that. There was a lot of denial too. I had to get through those two stages before I could accept what had happened and accept my child and the limitations he would put on my dreams. I had to come up with a new dream.

This next window shows me after I've learned to accept my child for who he is. I've learned to take all the backward glances and tasteless remarks in stride. I've seen ignorance from some people I used to think were intelligent and I've met some really wonderful people who I never would have known, had my child been normal. I've had to learn how to make people understand that my child is a child first and handicapped second.

I've seen miracles too. I've seen the first step the doctors said would never happen and I've seen the light of recognition in my child's eyes when he finally grasped the "meaning of something". And I've seen sunsets you wouldn't believe

once I had to really look at them and explain them to my blind child. What may seem ordinary to you has taken on a whole new significance for me.

I've learned a whole new language too. It's called "medicalese". Doctors tend to speak in words you don't hear every day. At first, I thought I'd never be able to keep all the terms and "isms" straight, but I speak it fairly fluently now. I'm beginning to learn "teacherese" now. You use a lot of abbreviations and numbers, but I know I can learn your language too.

Even though I've accepted my child, this next window will show you my fears for my child's future. I realize it's going to take a lot more effort if my child is to lead a fulfilling life. Learning may be difficult for him and in some cases, impossible, but I've really been trying to make his life as normal as possible. I try to focus on the abilities he has and I try to make him feel worthwhile.

I realize there are some things that my child can't do yet and he may never be able to do some things. Sometimes, I tend to focus too much on what he can do and not what he can't do, but it helps me and my family. Some days I seem to be taking three steps backward for every one forward.

You may only see the bad things about my child. It may not seem fair to you to spend more time with him or do things differently for one child, when you have a class room full of children who learn things in standard ways. My child may disrupt your class. He may not seem to be learning much. I don't expect you to ignore other students for his sake. I don't want him forgotten in a back class room with all the other "different" kids either, although he may have to spend some time in a smaller class room with more individual attention. My goal is to make his life as normal as I possibly can, and being around regular kids helps. It will take some understanding on both our parts to work this out. Perhaps some of your brighter students could help my child in some areas. You'll be teaching them about responsibility and they'll learn acceptance. They'll view handicapped children as children first and handicapped second. They may learn to accept my child before you do.

As a parent, I know I'm not perfect. I make mistakes every day. I realize teachers are only human too. I also remember the time when some of my teachers were up there with God, in my estimation. They had such an impact on my life! Your lives probably aren't as worry free or stress free as I used to think and my child may only add to a day that's too full and too underpaid. If you at least make the effort to try to treat my child as a person, I know how he will view you. Sit next to God for a while.

My attitude may not be the best you've seen lately. I may already have had some run ins with the "system" before I ever talk to you. I may come on too forcefully and seem too demanding. Maybe I've had to be to get services for my child. Maybe my sister-in-law has excluded my child and I from every family get

together she's had since I've had a "disabled" child. Maybe my husband isn't supportive. Or maybe the professionals I've dealt with before have done everything they could to help me. Maybe I'll assume that you will too, and I won't remember all the hard lessons I've learned along the way. Or I may remember each one too vividly. I may be a combination of all these feelings. Whatever the case, I am just a normal person who wants the best for my child.

I probably already know that my son won't grow up to be the captain of the foot ball team and my daughter won't be a Home Coming queen, but that doesn't mean that I don't have dreams for them. I've just substituted other dreams for those I've lost. We all harbor some pretty unrealistic expectations for our children and I'm no different than any other parent.

If I seem to want too much from you, I don't mean to. I may have a lot on my mind. I may not have totally accepted the direction my life has taken; it sometimes takes years for a parent to get to that point of acceptance. That's really not too hard to understand when you realize that I lived with that dream for most of my life, whereas I've lived with my "reality" for a lot shorter period. I may even be feeling cheated because my life seems so different from yours. There may be a lot of resentment in me. Or I could just be tired of fighting the battle. It may be that you have a better education and you may feel more qualified to make decisions about how and what my child will learn.

In most cases, you are the expert. But if you feel I'm realistic and I've accepted my child's limitations, there will be instances when I will know what will work best. In that case, I am the expert. I've learned some things that you should be thankful you've never had to learn.

If you take all the things you've seen through my windows into consideration, you may understand me and my child better. If we work together, maybe we can do what I pray for each night. That is to give my child as many opportunities as possible to lead a normal life, in a world that isn't fair.

*Copyright 2001 Pat Linkhorn*

---

**Pat Linkhorn** is the Editor of Special Education at About.com and a professional advocate for families with children who have special needs. She is also an experienced parent and has two girls with special needs - autism and blindness due to prematurity. <http://thelinkto.com/linkhome>

# To You, My Sisters...

By Maureen K. Higgins

Many of you I have never even met face to face, but I've searched you out every day. I've looked for you on the internet, on playgrounds and in grocery stores. I've become an expert at identifying you. You are well worn. You are stronger than you ever wanted to be. Your words ring experience, experience you culled with your very heart and soul. You are compassionate beyond the expectations of this world. You are my "sisters."

Yes, you and I, my friend, are sisters in a sorority. A very elite sorority. We are special. Just like any other sorority, we were chosen to be members. Some of us were invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail. We were initiated in neurologist's offices and NICU units, in obstetrician's offices, in emergency rooms, and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films, and heart surgeries. All of us have one thing in common. One day things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened in an instant, as it often does, or over the course of a few weeks or months, our entire lives changed. Something wasn't quite right. Then we found ourselves mothers of children with special needs. We are united, we sisters, regardless of the diversity of our children's special needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk, some are unable to walk. Some eat through feeding tubes. Some live in a different world. We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to be done, we know "the" degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology, and psychiatry. We have taken on our insurance companies and school boards to get what our children need to survive, and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children with cerebral palsy. We have labored to prove to insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive education and evaluation commensurate with their diagnosis.

We have learned to deal with the rest of the world, even if that means walking away from it. We have tolerated scorn in supermarkets during "tantrums" and gritted our teeth while discipline was advocated by the person behind us on line. We have tolerated inane suggestions and home remedies from well-meaning strangers. We have tolerated mothers of children without special needs complaining about chicken pox and ear infections. We have learned that many of our closest friends can't understand what it's like to be in our sorority, and don't even want to try.

We have our own personal copies of Emily Perl Kingsley's "Welcome to Holland" and Erma Bombeck's "The Special Mother." We keep them by our bedside and read and reread them during our toughest hours. We have coped with holidays. We have found ways to get our physically handicapped children to the neighbors' front doors on Halloween, and we have found ways to help our deaf children form the words, "trick or treat." We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and a blazing Yule log with our words for our blind children. We have pureed turkey on Thanksgiving. We have bought white chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family.

We've gotten up every morning since our journey began wondering how we'd make it through another day, and gone to bed every evening not sure how we did it.

We've mourned the fact that we never got to relax and sip red wine in Italy. We've mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we've mourned because we left for the airport without most of the things we needed for the trip.

But we, sisters, we keep the faith always. We never stop believing. Our love for our special children and our belief in all that they will achieve in life knows no bounds. We dream of them scoring touchdowns and extra points and home runs. We visualize them running sprints and marathons. We dream of them planting vegetable seeds, riding horses and chopping down trees. We hear their angelic voices singing Christmas carols. We see their palettes smeared with watercolors, and their fingers flying over ivory keys in a concert hall. We are amazed at the grace of their pirouettes. We never, never stop believing in all they will accomplish as they pass through this world.

But in the meantime, my sisters, the most important thing we do, is hold tight to their little hands as together, we special mothers and our special children, reach for the stars.

<http://www.arcfip.org/mysister.html>

**Knight Ridder News Service**  
**By Lori Borgman**

Expectant mothers waiting for a newborn's arrival say they don't care what sex the baby is. They just want to have ten fingers and ten toes.

Mothers lie.

Every mother wants so much more. She wants a perfectly healthy baby with a round head, rosebud lips, button nose, beautiful eyes and satin skin. She wants a baby so gorgeous that people will pity the Gerber baby for being flat-out ugly.

She wants a baby that will roll over, sit up and take those first steps right on schedule (according to the baby development chart on page 57, column two). Every mother wants a baby that can see, hear, run, jump and fire neurons by the billions. She wants a kid that can smack the ball out of the park and do toe points that are the envy of the entire ballet class. Call it greed if you want, but a mother wants, what a mother wants.

Some mothers get babies with something more.

Maybe you're one who got a baby with a condition you couldn't pronounce, a spine that didn't fuse, a missing chromosome or a palate that didn't close. The doctor's words took your breath away. It was just like the time at recess in the fourth grade when you didn't see the kick ball coming, and it knocked the wind right out of you.

Some of you left the hospital with a healthy bundle, then, months, even years later, took him in for a routine visit, or scheduled him for a checkup, and crashed head first into a brick wall as you bore the brunt of the devastating news. It didn't seem possible. That didn't run in your family. Could this really be happening in your lifetime?

There's no such thing as a perfect body. Everybody will bear something at some time or another. Maybe the affliction will be apparent to curious eyes, or maybe it will be unseen, quietly treated with trips to the doctor, therapy, or surgery. Mothers of children with disabilities live the limitations with them.

Frankly, I don't know how you do it. Sometimes you mothers scare me. How you lift that kid in and out of the wheelchair twenty times a day. How you monitor tests, track medications, and serve as the gatekeeper to a hundred specialists yammering in your ear.

I wonder how you endure the clichés and the platitudes, the well-intentioned souls explaining how God is at work when you've occasionally questioned if God



is on strike. I even wonder how you endure schmaltzy columns like this one-  
saluting you, painting you as a hero and saint, when you know you're ordinary.  
You snap, you bark, you bite. You didn't volunteer for this, you didn't jump up  
and down in the motherhood line yelling, "Choose me, God. Choose me. I've  
got what it takes."

You're a woman who doesn't have time to step back and put things in  
perspective, so let me do it for you. From where I sit, you're way ahead of the  
pack. You've developed the strength of the draft horse while holding onto the  
delicacy of a daffodil. You have a heart that melts like chocolate in a glove box in  
July, counter-balanced against the stubbornness of an Ozark mule.

You are the mother, advocate and protector of a child with a disability. You're a  
neighbor, a friend, a woman I pass at church and my sister in law. You're a  
wonder.

HAPPY MOTHER'S DAY

[http://web.odu.edu/webroot/instr/ed/pmyatt.nsf/files/Happy\\_Mothers\\_Day.pdf/\\$FILE/Happy\\_Mothers\\_Day.pdf](http://web.odu.edu/webroot/instr/ed/pmyatt.nsf/files/Happy_Mothers_Day.pdf/$FILE/Happy_Mothers_Day.pdf)